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ABSTRACT

A 4 year study is being conducted with 150 children (9 to 14 years old) to develop and evaluate a self management system for children with asthma. Ss receive a variety of educational "treatments" for their asthma, including information giving sessions, peer and family support groups, and relaxation training. Critical Incident Interviews, as well as contact with children participating in the study, have indicated that a significant obstacle faced by these children in preventing or controlling their asthmatic episodes is a general lack of understanding of their physical and emotional needs on the part of teachers and other school personnel. Data shows that the "successful self manager" is a child who has developed and exercises some measure of independence in self care, the ability to make appropriate decisions, skill in practicing compensatory behaviors, the ability to control stressful emotions, and the ability to resist detrimental peer and adult pressure. Among implications for school administrators, teachers, and support personnel are that there is a need for greater awareness by educators that chronic illnesses are handicaping conditions; that materials need to be developed that enable school personnel to deal appropriately with the special learning and social needs of the chronically ill child; and that mechanisms for improved communication and coordination between the school staff, parents, and medical personnel need to be developed. Statistics on critical incident categories are included. (SB)

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Special Educational Needs of Children with Chronic Disease

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Special Educational Needs of Children with Chronic Disease

Although children with chronic illnesses are categorized as "other health impaired" and thus are eligible for special educational services under Public Law 94-142 (the Education of All Handicapped Children Act), services for the chronically ill child who is able to function within the regular classroom environment are virtually nonexistent. It is true that such children are usually identified in school records, and most districts have some type of school nurse program to serve children's health needs. Nevertheless, there appears to be a serious lack of awareness of the needs of children with chronic diseases among the instructional staff. Without such awareness many of these children are at risk of school failure, inappropriate disciplinary actions, and even unintended physical abuse.

Empirical data from an ongoing study supports these contentions and the importance of increased school attention to the problems faced by children with such conditions as asthma, diabetes, epilepsy, hypertension, and sickle cell anemia. In recent years extensive resources have been devoted to teacher training or retraining, the development of special instructional materials and strategies, and the provision of special facilities for children with other handicapping conditions. Yet the chronically ill child continues to be largely unrecognized and unserved within the educational system, although these conditions often affect children's learning and social behaviors and impose restrictions on their daily activities.

The American Institutes for Research is now beginning the final phase of a four-year study, funded by the Division of Lung Diseases of the National Heart, Lung, and Blood Institute, to develop and evaluate a self-management system for children with asthma. The study includes approximately 150 children, ages 9 to 14, who are enrolled in the Kaiser-Permanente Medical Groups in Santa Clara County, California. They are receiving a variety of educational "treatments" for their asthma, including information-giving sessions, peer and family support groups, and relaxation training. Objectives for the various approaches were developed on the basis of a study conducted during the first year of the project, in which 565 parents, doctors, nurses, teachers, and children in three geographical areas were interviewed, using the critical incident technique, to determine

effective and ineffective self-management behaviors that occur outside of the medical setting. The interviews yielded 1,359 specific descriptions (called critical incidents) of situations in which a child took some action, or failed to take some action, that was clearly effective or ineffective in handling some aspect of asthma. (Table A shows the major categories and subcategories of behavior that were identified.)

The Critical Incident interviews, as well as contact with the children participating in the study during the past two years, have indicated that a significant obstacle faced by these children in preventing or controlling their asthmatic episodes is a general lack of understanding of their physical and emotional needs on the part of teachers and other school personnel. Interview data showed that the "successful self-manager" is a child who has developed and exercises some measure of independence in self-care, the ability to make appropriate decisions, skill in practicing compensatory behaviors, the ability to control stressful emotions, and the ability to resist detrimental peer and adult pressure. Yet many instances were reported in which children were hampered in practicing these behaviors by restrictions imposed by educators or school regulations. For example, it was not unusual for an asthmatic child to report that exercise-induced bronchospasm was brought on by being forced into physical activities that exceeded his or her limits. Being exposed to chalk dust or animals in the classroom or being made to sit by an open window precipitated attacks for many children. Several parents reported that medications prescribed for their children's asthma had made them listless or hyperactive and that teachers had misdiagnosed these states as attitudinal or behavioral problems. Some children were refused access to needed medications because school rules required that drugs be kept by the school nurse; teachers often decided that children should wait for a break in instruction before reporting to the nurse or the office. Some asthmatic children were ridiculed as "junkies", sissies, or malingerers by other students and teachers when they requested permission to take medications, attempted to observe physical limits, or sought help for bronchospasm. Many children tried to "hide" their asthma to avoid such repercussions.

Although the present study has been limited to the problems of children with asthma, there is reason to believe that similar obstacles may be encountered by children with other long-term, restrictive illnesses such

as diabetes or epilepsy. Most of these children are on some type of medication regimen and most of them must observe certain dietary and activity limitations. While it is important that each child be encouraged to develop interest and skill in physical activities and to expand their activities as much as possible, many of them cannot participate in activities at the same level as their peers, and thus are at risk of low self-esteem and lags in social and emotional development. Even with optimum medical management, the chronically ill child has a number of internal and external barriers to overcome in learning to accept his or her condition and to function at the fullest capacity.

The present situation has some obvious implications for school administrators, teachers, and support personnel. First of all, there is a need for greater awareness by educators that chronic illnesses are handicapping conditions. There is a need for better understanding of the type and extent of restrictions that are imposed by chronic disease. Materials need to be developed that enable school personnel to deal appropriately with the special learning and social needs of the chronically ill child. School structures and regulations need to be examined to determine if they provide the "least restrictive environment" for such children. Finally, mechanisms for improved communication and coordination between the school staff, parents, and medical personnel need to be developed so that chronically ill children receive consistent and appropriate care. School should not be hazardous to any child's health.

Table A Critical Incident Categories

CODE		# Incidents in Each Sub-category	Subtotal by Category
1	A. Prevention (349 incidents)		
1-01-00	1. Avoids allergens		
1-01-01	a. Foods	40	
1-01-02	b. Pollens	29	
1-01-03	c. Animal danders	38	
1-01-04	d. Dust	8	
1-01-05	e. Feathers, stuffings	3	
1-01-06	f. Fungal spores/molds	1	
1-01-07	g. Nonspecific/combinations of allergens	5	124
1-02-00	2. Avoids irritants and other precipitants		
1-02-08	a. Extremes in air temperature, humidity, barometric pressure or wind velocity	20	
1-02-09	b. Dampness	5	
1-02-10	c. Fumes (smoke, gas, chemicals, smog)	7	
1-02-11	d. Exercise	19	51
1-03-00	3. Controls or avoids emotions that trigger attack		
1-03-12	a. Fears, anxieties, or stress	42	
1-03-13	b. Anger, resentment, or jealousy	7	
1-03-14	c. Excitement	5	54
1-04-15	4. Takes action during or after exposure to allergen or irritant to minimize its effects	15	15
1-05-00	5. Takes preventive medicine or hyposensitization shots		
1-05-16	a. Routine	32	
1-05-17	b. Anticipatory	27	59
1-06-18	6. Ensures that medications for relief of symptoms are accessible	20	20
1-07-19	7. Uses some form of mind control to prevent attacks (self-hypnosis, creative visualization)	3	3
1-08-20	8. Cooperates in the treatment of upper respiratory infection to prevent asthma symptoms	23	23
2	B. Intervention (763 incidents)		
2-09-00	9. Takes ameliorative or corrective action when attack starts		
	a. Stops precipitating activity or leaves precipitating situation		

Table A (cont'd)

Code			# Incidents in Each Sub-category	Subtotal by Category
2-09-21		1) Removes self from allergens, irritants or precipitants (smoke, pollen, dander, dust, fumes, temperature extremes)	63	
2-09-22		2) Stops exercise or physical activity and rests or relaxes	118	(195)
2-09-23		3) Leaves anxiety-producing situation	6	
2-09-24		4) Changes the precipitating situation when impossible to leave	8	
2-09-25	b.	Takes medication/uses bronchodilating inhaler	90	
2-09-26	c.	Drinks fluids	21	
2-09-27	d.	Clears air passages (coughing, postural drainage, etc.)	22	
2-09-28	e.	Controls breathing, does breathing exercises	38	
2-09-29	f.	Improves ventilation in room/gets more air	8	
2-09-30	g.	Uses water vapor inhalation (steam or cool)	10	
2-09-31	h.	Positions body to ease breathing	25	
2-09-32	i.	Rests; engages in quiet activities	31	
2-09-33	j.	Uses biofeedback	1	
2-09-34	k.	Uses relaxation therapy	4	
2-09-35	l.	Treats associated symptoms (e.g., cold water on swollen eye)	8	
2-09-36	m.	Makes conscious effort to concentrate on something else	14	467
2-10-00	10.	Practices a variety of intervention strategies, depending on the progression/severity of symptoms		
2-10-37	a.	Decides whether intervention/help is needed and whether it should be immediate or can be delayed	36	
2-10-38	b.	Tries another intervening action when first action is ineffective	17	
2-10-39	c.	Seeks help from family members or other adults when own interventions don't work	7	
2-10-40	d.	Requests specific therapy from intermediary, when required	73	
2-10-41	e.	Reports symptoms to adult and relies on adult for intervention	69	
2-10-42	f.	Seeks medical help when self-treatment measures do not work	21	223
2-11-43	11.	Develops or requests individually adaptive intervention	8	8
2-12-00	12.	Uses medicines correctly		
2-12-44	a.	Recognizes undesirable side effects of medication and reports same	4	
2-12-45	b.	Takes medicines in proper dose, at correct intervals, and under prescribed conditions	15	19
2-13-00	13.	Remains calm during attack		
2-13-46	a.	Stays calm; controls emotions (fear, anger, anxiety)	41	
2-13-47	b.	Relaxes and allows medicine to work	5	46
3	C.	Compensatory Behaviors (199 incidents)		
3-14-48	14.	Discusses asthma with peers, makes them understand restrictions, and seeks/accepts peer support	15	15

Table A (cont'd)

CODE		# Incidents in Each Sub-category	Subtotal by Category
3-15-00	15. Accepts primary responsibility for managing own condition		
3-15-49	a. Reconciles strong personal desire in order to avoid precipitation or exacerbation of symptoms	22	
3-15-50	b. Reminds adult of treatment schedule	3	
3-15-51	c. Alerts adult about possibility of attack	10	
3-15-52	d. Relies on own resources	13	
3-15-53	e. *Does not know what to do in case of attack*	6	54
3-16-00	16. Exhibits determination to overcome limitations or expand capabilities		
3-16-54	a. Participates in physical activities according to capabilities, e.g., modifying activity or pacing self	41	
3-16-55	b. Builds up tolerance to allergen or exercise	6	
3-16-56	c. Has developed creative alternatives to restrictions posed by asthma	14	61
3-17-57	17. *Denies, resents, hides or blames self for asthma*	9	9
3-18-58	18. Accepts/cooperates with regimen even if painful, frightening or restrictive	14	14
3-19-00	19. Avoids using the asthma to manipulate people/get attention		
3-19-59	a. Avoids conscious precipitation of attack or use of symptoms to manipulate others	45	
3-19-60	b. Minimizes own problem to help another	1	46
4	D. External Controlling Factors (48 incidents)		
4-20-00	20. *Treatment hindered by figures in authority*		
4-20-61	a. *Adult forced the child to do something detrimental in terms of the asthmatic condition*	11	
4-20-62	b. *Parent used child's asthma to manipulate child*	2	
4-20-63	c. *Adult failed to assist the child or to comply with protocol/therapy*	17	
4-20-64	d. *Adult denied the attack*	3	
4-20-65	e. *Adult fostered child's dependency on others for treatment*	3	36
4-21-66	21. *Family problems triggered child's asthmatic attack*	12	12
	TOTAL NUMBER OF USABLE INCIDENTS		1359
5	E. Unusable Incidents		
5-22-00	22. Incidents which were not used in the analysis		
5-22-90	a. Not about asthma	3	
5-22-91	b. Not right age group	2	
5-22-92	c. Not enough detail	7	
5-22-93	d. Generalization	3	15
	TOTAL NUMBER OF INCIDENTS		1374